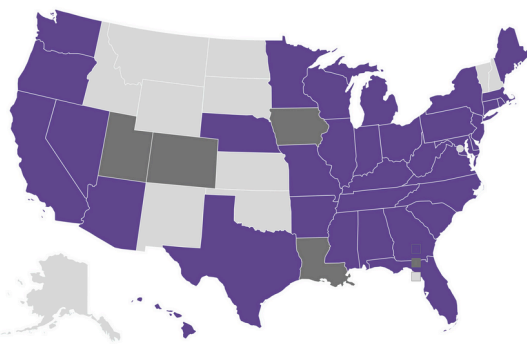# ALZHEIMER'S NETWORK
ALZHEIMER'S ASSOCIATION®

SUMMER 2025 NEWSLETTER

ALZ-NET Sites

113 ActiveSites (Purple)
134 Sites in Start-Up (Dark Gray)
2771 Patients Registered
As of August 18, 2025

Join us in welcoming the newest ALZ-NET Sites

- Raleigh Neurology Associates P.A., Raleigh, NC
- Southern Illinois University School of Medicine, Springfield, IL
- Semmes-Murphey Clinic, Memphis, TN
- BayCare Health System - St Anthony's Hospital, St. Petersburg, FL
- ProHealth Care, Waukesha, WI
- University of California, Irvine Neurology, Irvine, CA
- RCH Brain & Mind Center IL, P.C., Chicago, IL
- Brain and Spine Surgeons of Orange County, Newport Beach, CA
- RCH Brain & Mind Center VA, P.C., Fairfax, VA
- USC Memory and Aging Center, Los Angeles, CA
- Loma Linda University Health Department of Neurology, Loma Linda, CA
- Atrium Health Wake Forest Baptist, Winston-Salem, NC
- RCH Brain & Mind Center TX, PA - Fort Worth, Fort Worth, TX
- RCH Brain & Mind Center TX, PA - Houston, Houston, TX
- Broward Health North, Deerfield Beach, FL

Operations Updates

New! Data Quality Management Program
- The ALZ-NET Data Management Team implemented two new data quality initiatives on July 1:
  1) Informed Consent Review
  2) Quarterly Data Compliance Assessments
  Here is what to expect.
- Questions about your data compliance score? Contact the ALZ-NET Data Management Team at **alznet-data@acr.org**.

New! ALZ-NET Data Dashboard
- A dynamic, user-friendly analytics and data visualization platform. Sites will gain login access to site-level data in Sept. 2025 to:
  - Explore clinical patterns.
  - Monitor emerging ARIA event trends.
  - Uncover actionable data entry insights.
  - Inform patients about ALZ-NET's progress and their contributions to Alzheimer's science.
  View the public dashboard.

eConsent Guidance For Participating Sites
- Practices engaging in remote consent activities must comply with Advarra's regulations for remote consent in ALZ-NET. Prior to engaging in remote informed consent with patients, please review **ALZ-NET's Guidance for Electronic and Remote Informed Consent**.

Resources for Sites

Explore the ALZ-NET Data Collection webpage, which includes training modules, helpful resources and quick guides to ALZ-NET data entry and submission.

Tips and Tricks

- Registering a new patient? Make sure the treating clinician is a registered staff member on the Site Staff List.
- Save your work! The ALZ-NET Portal logs out users after 20 minutes of inactivity.
- Having trouble navigating Medidata Rave? Review the **eCRF Training Module** or join ALZ-NET Office Hours for a quick demo.
- DO NOT pre-print ICFs. Print directly from Advarra CIRBI once needed to ensure using correct IRB approved version.
- DO NOT attempt to enroll patients at the same time using different browsers. This will result in registration errors.

Join Us at CTAD

Date: December 1-4
Location: San Diego and online

ALZ-NET leadership will publicly share data from the registry for the first time at our session at the Clinical Trials on Alzheimer's Disease (CTAD) meeting. **Register today** to learn more about data trends, connect with other sites and hear about plans for ALZ-NET data access.

Save the Date

Attending the AAN Annual Meeting? Keep an eye on your inbox for details on how to connect with your ALZ-NET community onsite.

Highlights and Key Takeaways from the ALZ-NET Meeting at AAIC
Connecting the Clinical Community: July 26, 2025 - Toronto, Canada

Important Reminders
- ALZ-NET is a direct pathway for Medicare coverage.
- In September, ALZ-NET Sites will be able to access their site-level data in real-time in the newly launched ALZ-NET Data Dashboard. Sites are encouraged to preview aggregate Network-wide statistics **here**.
- ALZ-NET's Data Request Process for access to Network-wide data will be available at the end of 2025.

Opportunities for Sites to Improve Operational Efficiency
- Flag Eligible Patients Early: Set up an internal system to identify potential participants before their visit, especially those already on therapy, to enable real-time consenting and avoid follow-ups.
- Streamline Documentation: Use smart phrases and note templates based on ALZ-NET Case Report Forms to simplify data entry. **Preview examples here**.
- Leverage Office Hours: Join weekly ALZ-NET office hours to resolve data entry issues and optimize workflows.
- New Staff? Contact the ALZ-NET Operations Team (**alz-net@acr.org**) to schedule a protocol training.

New Patient Recruitment Materials – Coming Fall 2025
- ALZ-NET will release patient-facing materials to support recruitment. These will be submitted to Advarra IRB on behalf of the site.
- Have your own materials? Request the ALZ-NET Logo Toolkit by emailing **alz-net@acr.org**.
- All custom materials must be approved by ALZ-NET per the **ALZ-NET Advertising Policy**.

The Role of Radiology in Alzheimer's Care and Research
- High-quality radiology reads are essential for diagnostic accuracy, clinical decision making, and longitudinal research.
- Share ALZ-NET's **imaging resources** with your imaging facilities.
- Is your imaging facility part of the ALZ-NET Imaging Network? **Refer them today**.

Frequently Asked Questions
Q. How does ALZ-NET manage patients who receive care at multiple clinics due to travel?
A. The clinic that obtains patient consent and completes the registration in ALZ-NET is responsible for coordinating care across sites. This includes requesting and reviewing medical records from any additional clinics the patient visits, both to ensure accurate data entry and to support best practices in clinical care.

Q. Does ALZ-NET plan to collect blood-based biomarkers?
A. Yes. ALZ-NET plans to add a biorepository component in a future version of the protocol. Sites will be notified via email when this option is available to their patients.

Site Spotlight: LGHP Alzheimer's and Memory Care Penn Medicine Lancaster General Team

What does being part of the ALZ-NET Registry mean to you, and what advice do you have for other sites to help ALZ-NET operations go smoothly?
It gives us great professional satisfaction knowing that we are a part of this national research community in learning more about current therapies for Alzheimer's and potential alternative treatments for this prevalent disease process. It provides us with an opportunity to participate in meaningful work for both our patients and future generations. Patients have been very excited to participate. They feel like they are part of a meaningful and cutting-edge program that is advancing the science of memory care.

What challenges did you overcome when implementing ALZ-NET at your site?
There were initial challenges in onboarding the study since the providers and clinical staff were new to clinical research. The other challenge we encountered here at LGH was access to TRIAD, which led to an influx of queries. We are continuing to work on this with our Research colleagues. Our current challenges are unrelated to enrollment or our patients. The start-up process for our site was difficult at first since we were building a foundation for collaboration between the Memory Care Center and the Research Institute. Since we have built connections between departments, we now have a strong collaborative relationship with the PI and office manager from The Memory Care Center. This collaborative effort with a dedicated PI, clinical staff, and research staff has helped the enrollment process here at LGH. Additionally, we chose to have a virtual SIV with ALZ-NET Operations to create an open forum for questions and the development of workflows. This meeting officially laid the groundwork for us to begin enrolling just one week after the SIV occurred.

What advice do you have for other sites to help ALZ-NET operations go smoothly?
Be proactive in obtaining access to TRIAD, ensure all coordinators receive adequate training for data entry, utilize the weekly ALZ-NET office hours, and prepare an internal checklist for entering all data – this helped immensely! Also, the most beneficial thing at our site has been our well-established communication between our PI, research coordinators, and clinical staff. It is also beneficial to have several up-front meetings with research support personnel so you can each understand each other's roles and workflows.

How has it been enrolling patients?
We have had only positive experiences so far with enrollments. Patients are very interested in this work and learning about outcomes that can potentially help themselves and their families (kids, grandkids, etc). We also have a great relationship with our PI and clinical team at the Memory Care Center, making enrollment more consistent with a direct line to patients. Our PI and clinical staff are just as passionate about research as our own research team and the patients, making enrollment successful so far at LGH.

Support for Sites
The ALZ-NET Operations Team at the American College of Radiology is available for network support, including protocol training, at any point during your participation in ALZ-NET. Office Hours are hosted twice every week on **Zoom**. No appointment needed on Tuesdays from 12-2 p.m. EDT, or Wednesdays from 2-4 p.m. EDT.

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